Ageing and Disability Commission

NSW GOVERNMENT

Neglect of older people and adults with disability in NSW

Key findings and themes from reports to the NSW Ageing and Disability Commission (ADC)

Abstract

Neglect of older people and adults with disability in New South Wales is a pervasive, complex issue, often intertwined with coercive control, abuse, and social isolation. Drawing on analysis of 474 reports to the NSW Ageing and Disability Commission (ADC), this research by the University of NSW Social Policy Research Centre (SPRC) reveals that neglect is frequently perpetrated by family members (including intimate partners) — most often primary carers — and is exacerbated by factors such as carer stress, poor health literacy, and barriers to accessing services. Nearly half of those affected are socially isolated, heightening both their risk and the severity of neglect. Service involvement, especially from aged care and disability providers, is a protective factor, yet serious neglect cases often lack such support.

The findings underscore the urgent need for early intervention, improved service coordination, and greater awareness of criminal neglect, with a call to action for health professionals, service providers, and policymakers to proactively identify, prevent, and address neglect — guided by the views and wishes of those at risk.

Introduction

The Ageing and Disability Commission (ADC) handles reports about older people and adults with disability who are subject to, or at risk of, abuse, neglect or exploitation in their family, home and community. Around one quarter of the reports involve allegations of neglect. Neglect is the third most common concern reported in relation to older people, and the second most common concern reported in relation to adults with disability.

The causes of neglect of older people and adults with disability, and the factors involved in these matters, are generally poorly understood. The National Elder Abuse Prevalence Study report noted that, as neglect has characteristics that distinguish it from other forms of abuse, 'more in-depth understanding of how it arises and how it may be addressed, including through overcoming barriers to help seeking, is warranted.'[1]

In 2024-25, the ADC commissioned the University of NSW Social Policy Research Centre (SPRC) to undertake research into neglect of older people and adults with disability. The NSW Department of Communities and Justice provided funding for this research which included a literature review and analysis of de-identified data from reports to the ADC over a two-year period that involved alleged neglect of an older person or adult with disability in their family, home and community. Reports involving alleged neglect by paid staff were excluded.

The main data analysis focused on 474 reports to the ADC about alleged neglect of older

[1] Australian Institute of Family Studies (2021) *National Elder Abuse Prevalence Study*, p170.

people and adults with disability in NSW, that were primarily handled by the ADC's Community Supports and Investigations Unit and closed between 2021 and 2022. This report summarises the key findings from this analysis along with themes arising from the ADC's broader handling of reports involving neglect.

The full SPRC research report on Neglect among Adults with Disability and Older People in NSW is available here: http://doi.org/10.26190/unsworks/31553

What were the characteristics of the older people and adults with disability who experienced neglect?

- Two thirds were older people, including older people with disability. Their average age was 81 years. Most (68%) were female.
- One third were adults with disability (who were not older people). Their average age was 38 years. Over half (52%) were male.
- Half had severe or profound core activity limitations in their communication, self-care or mobility. Over half (59%) had 1-2 chronic health conditions.
- In relation to cultural background, 15% had a primary language that was not English, and 5% were Aboriginal.

What were their circumstances prior to the report about neglect?

- Three quarters lived in their own home and lived with the person who was the subject of the allegations.
- Over half (59%) lived in a regional area of NSW.
- For 19% of the older people and adults with disability, the concerns involved lower-level neglect relating to their needs not being met.
- For three-quarters (77%) of the adults, their circumstances were more serious:
    - Half were showing signs of neglect[2].
    - A further quarter were in a poor condition[3], very unwell[4], or critically unwell[5] at the time of the report to the ADC.
- Nearly half (44%) were socially isolated.

What was the nature of the neglect?

Many of the reports involved more than one form of neglect. The most common form of alleged neglect involved a failure to meet the person's support needs, such as their personal care, mobility, or other support need (73%).

[2] 'Signs of neglect' included where the Person was starting to show signs of potential neglect, such as where they had stained clothing, were unwashed, and/or did not have any food or money.
[3] 'Poor condition' included where the Person was covered in faeces, was unwashed, had matted hair, had threadbare, filthy or no clothing, and/or had untreated medical issues.
[4] 'Very unwell' included where the Person required medical assistance and likely hospital admission to avoid becoming critically unwell (such as dehydrated, malnourished, high grade pressure areas).
[5] 'Critically unwell' included where the Person was in a life-threatening condition requiring urgent medical assistance and hospital admission (such as unconscious, seriously dehydrated/malnourished, sepsis).

One third of the reports involved alleged medical neglect, such as a failure to get medical assistance, provide prescribed medication, or follow-up on recommended treatment.

In 17% of reports, the person was alleged to have inadequate clothing and/or food.

In 8% of reports, the neglect involved a failure to provide the necessities of life (criminal neglect).

In 38% of reports, the person experienced 'serious neglect'. This was where:

- the person was very unwell or critically unwell at the time of the report to the ADC, and/or
- the allegations included that there was a 'failure to provide the necessities of life', and/or
- the case had been referred to police by the ADC in relation to neglect, and/or
- the person died prior to case closure and related to the neglect event(s).

Who were the subjects of allegation?

The subjects of allegation (the parties who were alleged to be neglecting the needs of the older person or adult with disability) were mainly relatives. This was the case in relation to 68% of the reports about older people and 74% of the reports about adults with disability.

In relation to older people, the subjects of allegation were:

- mainly their adult child (62%), intimate partner (22%), or sibling (4%)
- more often male (56%) than female (40%).

In relation to adults with disability, the subjects of allegation were:

- mainly their parent (52%), intimate partner (20%), or sibling (13%)
- more often female (55%) than male (41%).

Most of the subjects of allegation (71%) were the person's primary carer.

Was there service involvement prior to the report about neglect?

Many individuals had the involvement of an aged care or disability service, but fewer had contact with health services. In the six months prior to the report to the ADC:

- 63% had the involvement of aged care or disability services
- 43% had contact with a General Practitioner (GP)
- 37% had contact with a hospital
- 18% had contact with a community health service.

More adults with disability had the involvement of a disability service prior to the report to the ADC (67%) than older people had the involvement of an aged care service (38%).

Service involvement was lower for the people who experienced serious neglect. In these cases, in the six months prior to the report to the ADC:

- 45% did not have the involvement of any aged care or disability services
- only 39% had contact with a GP.

What factors contributed to the neglect?

Coercive control and abuse contributed to the neglect in many reports:

- In 51% of reports, the subject of allegation actively prevented or restricted the person's access to necessary services, such as ageing, disability and/or health services.
- In 38% of reports, the neglect was associated with current and/or historical abuse in the relationship between the person and the subject of allegation. This included current or previous domestic violence.

The reports in which current and/or historical abuse contributed to the neglect were more likely to involve serious neglect. Abuse was a contributing factor in almost half (47%) of the reports involving serious neglect.

In 41% of reports, carer stress was a contributory factor.

In 13% of reports, health literacy (of the person, the subject of allegation, and/or other family member) was a relevant factor in the neglect.

In a lower proportion of reports (9%), a delay in accessing services contributed to the neglect. The causes of the delays included:

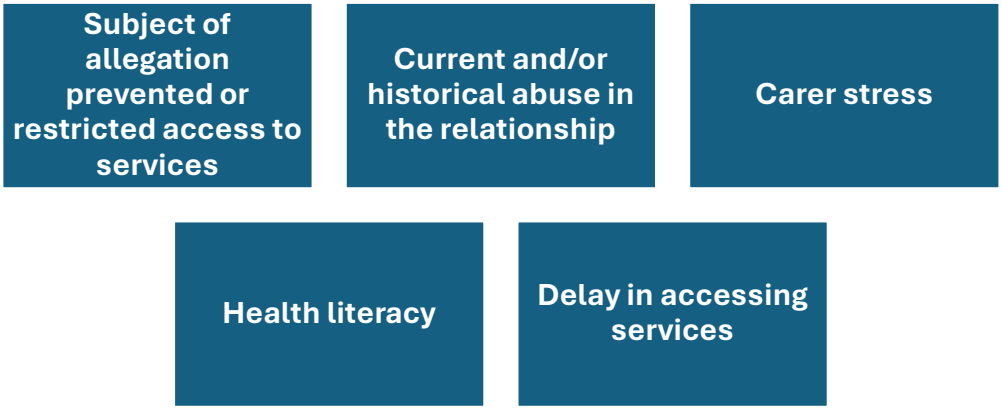
- service system capacity issues
- the actions of providers or practitioners (such as delays in making or following up on referrals)
- the actions of the person, subject of allegation, or family (e.g. not taking the next step to arrange services).

A delay in accessing services was a more significant factor for older people with dementia, contributing to neglect in 14% of cases, compared with 7% for people without dementia. The delay was most often due to the actions of the person, the subject of allegation, or family rather than service capacity.

Most of the factors contributing to neglect were more common in relation to the people who were socially isolated, including:

- the subject of allegation actively preventing the person from accessing services (66%)
- current or historical abuse in the relationship (52%)
- carer stress (51%)
- health literacy (20%).

Figure 1: Factors contributing to the neglect



What factors affected the response to the neglect/ the person's situation?

This research considered the factors that affected the response of any individual or agency to the person's situation/ the neglect. The main factors were:

- the person's views and wishes
- the subject of allegation refused help/ refused to act
- the parties did not realise the seriousness of the situation
- the subject of allegation did not know what to do
- the person had recent hospital or other medical contact

The most common factor affecting the response was the views and wishes of the older person or adult with disability, identified in almost half (46%) of the reports. This included, for example, where:

- the person refused offers or actions to obtain medical or other help
- the person was unable to indicate a view but had a history of refusing help or outside intervention.

In a quarter of the reports (23%), the response to the person's situation was affected by the subject of allegation either refusing the help of others or refusing to take action themselves.

In 22% of reports, the response was affected by parties not realising the seriousness of the person's situation. Depending on the case, this included the subject of allegation, relatives, service providers, and/or the person themselves.

In 12% of reports, the subject of allegation did not know what to do in response to the person's situation.

In a lower proportion of reports (9%), the response to the person's situation/ the neglect was affected by the person having had recent hospital or other medical contact. For example, the person's family assumed that the medical professionals would have taken other action (such as sending the person to, or keeping them in, hospital) if they were worried about the situation.

Current or historical abuse in the relationship between the person and the subject of allegation also affected the response to the neglect. In cases where abuse contributed to the neglect, the response was more likely to be affected by:

- the views and wishes of the person (56%)
- the subject of allegation refusing help or refusing to act (31%).

Key findings and areas for further action

1. There are important links between neglect, coercive control and other abuse

This research identifies links between neglect, coercive control and other forms of domestic violence that are important to understand to better prevent and address neglect of older people and adults with disability. In particular:

- Coercive control and/or other abuse of the person both increases their risk of neglect and affects the response:

    - It can cause or contribute to the neglect situation, including via deliberate actions to isolate the person; to refuse to provide necessary support; and to prevent, restrict or delay access to external services.
    - The existence of abuse can also sustain neglect and make it harder to address. This includes the isolation of the person making it harder to identify the neglect to enable a response; the subject of allegation refusing to act and refusing help; and the person denying any issues and refusing external assistance because they are afraid of escalating the situation and retribution by the subject of allegation.
- Neglect is not just about unmet needs and a lack of action. While some of the ADC's cases do involve parties being out of their depth and not knowing what to do, in many cases, the person's needs are not being met, and their health and safety are at risk, because of the intentional actions of someone they trust.
- Understanding the relationship between the person and the subject of allegation can be key to preventing and addressing the risk of neglect. If there are indications that the relationship is currently abusive (including coercive and controlling behaviours), or there is a history of abuse, the risk of neglect is higher.
- Social isolation can be both the result of abuse (the person is intentionally cut off from others and help) and a means through which abuse is perpetrated (abuse can occur unchecked and unseen by others). This research identifies that this is also the case with neglect. Social isolation can be an important indicator of, and a significant risk factor for, neglect of older people and adults with disability.

This research and the work of the ADC highlights the need to ensure that:

- early action is taken in response to potential neglect
- active and early consideration is given to the nature of the relationship between the person and their main household/ family member(s)
- where there are concerns about potential neglect, actions are taken to explore and identify the underlying factors, including potential coercive control or other abuse
- suspected and actual abuse is identified and addressed at an early point, guided by the views and wishes of the person
- where there are indicators or risk factors for neglect or abuse, the person is proactively connected to service coordination/linkage assistance (such as a Care Finder or support coordinator)
- there is adequate consideration of, and access to, relationship support and counselling services.

2. Social isolation is a major risk factor for neglect and should be a red flag

The research identifies that people with disability and older people who are socially isolated are at greater risk of neglect, and there is a greater risk of that neglect being more serious.

In our data, 44% of the reports involved people who were socially isolated. They were more likely to have a core activity limitation (higher support needs), less likely to have formal supports (aged care, disability or health service involvement), and less likely to be receiving informal support (such as from other family or friends).

For the people who were socially isolated, the subject of allegation was also more likely to have prevented their access to services and have carer stress, and it was more likely that there was current or previous abuse in the relationship.

It is vital that social isolation of older people and adults with disability is actively considered and identified, the reasons for the isolation are explored and understood, and steps are taken to address the isolation and the contributory factors.

3. Aged care and disability service involvement is a protective factor, but earlier actions to prevent, detect and respond to neglect are needed

The involvement of disability or aged care services can be a protective factor against neglect, particularly in halting the course and reducing the impact of neglect. In this research, those who experienced serious neglect were less likely to have the involvement of these services, including 45% who did not have any recent involvement.

However, in the experience of the ADC, often the main action by involved services has been to make a report to the ADC. While this action is positive, there is also a need to increase the knowledge and capability of services on other, and earlier, actions they can and should take to reduce and address neglect of the adults with disability and older people they support.

For example, in reports involving alleged neglect, the ADC has noted services:

- deferring to the subject of allegation for decision-making instead of their client, enabling subjects of allegation to decline, cancel or reduce services, and prevent services from facilitating access to medical help
- not having conversations with the person or the subject of allegation/ family about their concerns to better understand the factors involved and the wishes of the person, or to provide an opportunity for behaviour change
- withdrawing support to the person due to the perceived risk to their staff or service, notwithstanding high and increasing risks to the person.

4. Safety by design principles need to be embedded in systems which support older people and people with disability to prevent neglect

This research and the work of the ADC identifies the need to embed safety by design principles, including:

- clear and enhanced guidance for aged care and disability services on preventing, identifying and responding to potential neglect, including clarity on when to escalate
- in-person contact to be the default requirement for service provision (particularly for people with high support needs), including guidance on minimum expectations, and actions to take in response to perceived WHS risks
- greater weight on, and improved practice in, supporting the person to make and uphold their own decisions – including through supported decision-making.

5. Contact with health services and practitioners is critical for preventing and addressing neglect, but it is not reliably occurring

Our data identified low levels of involvement of health services with the adults with disability and older people who were reported to the ADC in relation to neglect, including with GPs (43%), hospitals (37%) and/or community health services (18%). The data was even more alarming in relation to people experiencing serious neglect, where only 39% had contact with a GP in the six months prior to the report to the ADC.

6. Guidance to improve health service and practitioner responses is needed

The research has highlighted the need to:

- support GPs to better identify and respond to potential neglect, such as through the use of a screening tool, and a targeted education campaign
- explore options to proactively identify and follow-up with older people and adults with disability at risk of neglect who have not had recent GP contact
- consider the adequacy of guidance and tools in hospitals to identify potential neglect on presentation/ admission and prior to discharge
- better factor the health literacy of the person at risk of neglect and their identified carer into health recommendations and follow-up.

In many cases, the report to the ADC about neglect has been made when the person is on the way, or has recently been admitted, to hospital, often in a poor state. In the ADC's experience, neglect is seldom considered by health staff in their assessment and actions in relation to the person until prompted by ADC staff. The research identified that health services actively considered neglect in their response to the person's presenting condition in only 35% of relevant cases.

This research and the work of the ADC highlights the need for clear guidance and protocols in Local Health Districts for identifying and responding to potential neglect of older people and adults with disability, including:

- indicators of potential neglect
- referral and reporting pathways
- identifying and responding to potentially criminal neglect.

The ADC has also identified opportunities for greater involvement of community health services in matters involving neglect. The low level of engagement captured in the data is consistent with the ADC's broader experience and reflects a number of factors, including:

- the person's lack of contact with relevant health practitioners/ services that could make a referral to community health services
- closure of the referral due to lack of engagement by the person, subject of allegation, carer or family
- closure of the referral due to the perceived WHS risk to staff associated with the person's home.

When delivered, community health services provide valued and vital support to older people and adults with disability at risk of, or subject to neglect, including health treatment and monitoring, guidance for carers, and connection to additional services. To improve the connection to, and the likelihood of support from, community health services, there is a need to:

- review the adequacy of guidance on referrals to community health to ensure that people at risk of neglect are identified and connected to the right support at the right time
- provide guidance on the minimum actions required prior to closure of a referral where there are concerns about, or risk factors for, neglect
- ensure that in-person contact is the default requirement for service provision, including guidance on minimum expectations, actions to take in response to perceived WHS risks, and revision of risk thresholds.

7. The views and wishes of the person can affect actions to prevent and address neglect

The current or previously expressed views, wishes and actions of the person in relation to services and supports can prolong neglect and adversely affect actions to address the situation. This includes the person refusing services, the involvement of external parties, and/or medical assistance. In addition to the person not getting the support they need, it can mean that family or carers are put in the invidious position of deciding whether and at what point they should go against the person's wishes to get help.

In reports involving neglect handled by the ADC, there has been a range of reasons why the older person or adult with disability has refused or otherwise indicated they did not want help, and understanding these reasons has been critical to informing the response. Common factors influencing the person's views and wishes have included:

- **Fear that they will have to go into residential care.** In a high volume of neglect reports handled by the ADC, the person's refusal of support relates to their concerns that if they go to hospital or an external professional or provider considers that they cannot manage at home or the carer/family is not meeting their needs, they will be forced to move into residential care and no longer be able to remain at home. In a range of cases, this is also the message that the subject of allegation has communicated to them in the context of coercive control.
- **Coercive control and other abuse.** This includes where the person has refused assistance or indicated that they do not need help because they are afraid of the subject of allegation and escalating the abuse.
- **Shame.** In a range of cases, the person has refused contact with external services as they have been ashamed of their poor living conditions (sometimes including squalor and hoarding by the person or subject of allegation) and/or the fact that they are subject to abuse or neglect by their family or intimate partner.
- **Grief and mental health needs.** For some older people and adults with disability, the refusal of assistance and intervention has been associated with their mental state. This has included people who have refused all contact after the death of a significant other or had other unmet mental health needs that have affected their insight and engagement.

8. Understanding and addressing the reasons why the person may be refusing help can be key to preventing and addressing neglect.

The research and experience of the ADC highlights that understanding and addressing the reasons why the person may be refusing help or resistant to medical or other intervention can be key to preventing and addressing neglect. While the will and preference of the person are paramount, this research has identified that in a range of cases, the person had previously refused services or other actions but accepted after a discussion with the ADC (or social worker or other professional).

The research has also pointed to the need to:

- promote service use to the person and their carer/ family as a means to maintain independence
- ensure the provision of a person-centred, trauma-informed and sensitive approach with the person and their household to build trust and support continued engagement
- ensure there is greater awareness of coercive control of adults with disability and older people, and proactive steps to prevent, identify and address it
- proactively connect the person to third party support brokers/ coordinators

- emphasise connection to services, community and relationships as protective factors
- improve the timeliness and adequacy of access to formal supports at home.

9. Not all neglect is intentional

The research identifies that relevant factors contributing to and affecting the response to neglect include those related to the needs of the carer or broader household members. In particular:

- carer stress
- their own support needs, including in relation to mental health, disability, ageing, and housing
- their health literacy
- their knowledge of what to do and where to get help.

In relation to carer stress, our data identified that it was a contributory factor to neglect in 41% of the reports, and this was exacerbated in cases of social isolation, where carer stress was relevant to the neglect in 51% of those reports. The research also identified that cases in which carers were stressed tended to involve less serious neglect, suggesting that the risk of neglect may start to show first through carer stress.

The research underscored the importance of actively considering the needs of the carer at an early point to help prevent and effectively respond to potential neglect.

10. There is a need for a joined-up approach to identifying adults with disability and older people who are at risk of neglect

This research identified that many of the adults with disability and older people in reports to the ADC involving neglect had high support needs, including half who had severe or profound core activity limitations. Despite their high support needs, they also tended to be:

- socially isolated
- not adequately connected to direct care services, such as ageing or disability support
- not adequately connected to a GP or other health services.

For older people and adults with disability with high support needs, there is a reasonable expectation of the care and support they would need and should be receiving. The need for, and access to, support is typically informed by assessment (such as aged care, NDIS, GP/health, carer assessments), and there are data and records relating to the outcomes of the assessments and any formal supports being accessed. Relevant data and other information can include, for example:

- NDIA information holdings on people with disability who have been assessed as eligible for NDIS supports, and their use of services
- information held by aged care assessment services and My Aged Care on older people who have been assessed as eligible for aged care supports, and any engaged services
- GP and health service records
- Services Australia information holdings relating to payment of the aged or disability support pension, carer payment, and Medicare claims.

However, the research indicates that there are currently inadequate mechanisms for proactively identifying older people and adults with disability with high support needs who

are not receiving the necessary support. For example, to be able to flag individuals with high support needs who:

- were referred by their GP for an aged care or NDIS assessment but were not assessed and had no further contact with their GP
- had an assessment identifying their eligibility and need for aged care or disability supports but were never linked to and/or started receiving any services
- were receiving aged care or disability services but stopped receiving this support
- have frequent changes or repeated cancellation of services
- have someone who is receiving the carer payment to provide support to them but have had no recent Medicare or Pharmaceutical Benefits Scheme claims.

There is a need for a more joined-up approach to identifying adults with disability and older people who are at risk of neglect, using existing data, and connecting to safeguarding pathways. Where the data or flags identify that the supports are not consistent with what would be expected or reasonable for the person's needs, this should trigger specific actions, including inquiries (at a minimum) and a proactive approach to support – such as the direct engagement of an aged care Care Finder service, an NDIS support coordinator, and potential referral to the ADC (or other adult safeguarding agency).

11. There is a poor understanding of criminal neglect of adults in NSW

The NSW *Crimes Act 1900* includes criminal offences relating to serious neglect, most of which relate to neglect of children. However, section 44 of the Crimes Act, 'Failure of persons to provide necessities of life,' is not limited to children, and provides that:

> (1) A person —
>
> (a) who is under a legal duty to provide another person with the necessities of life, and
>
> (b) who, without reasonable excuse, intentionally or recklessly fails to provide that person with the necessities of life,
>
> is guilty of an offence if the failure causes a danger of death or causes serious injury, or the likelihood of serious injury, to that person.
>
> Maximum penalty — Imprisonment for 5 years.

There are also other offences in the Crimes Act that can be relevant to some matters involving serious neglect of an adult, including reckless grievous bodily harm, and manslaughter by gross criminal negligence.

In handling reports involving serious neglect of older people and adults with disability, the ADC has identified that there is poor awareness of the fact that there are criminal offences relating to serious neglect of adults, and there is a poor understanding of the proof that is required to meet each element of the section 44 offence.

While the ADC has noted increased awareness by police of criminal neglect in relation to older people and adults with disability, there is a paucity of NSW case law involving successful prosecution of these matters. A failure to adequately understand and prove the elements of the offence has been relevant in more recent cases.

The work of the ADC has identified the need to:

- Increase the awareness and understanding of police and health services in relation to criminal neglect of older people and adults with disability and the elements

involved, to enable early identification of, and action on, relevant matters, and support successful prosecutions.

- Improve public awareness that neglect of older people and adults with disability can be a crime, and that these matters will be pursued. At a minimum, greater public awareness may provide a useful impetus in some cases for families and carers to take action to link the person with supports and to seek timely medical assistance.

In relation to the latter, it will be important that this messaging is also in the broader context of providing public guidance and support for relatives to be better able to:

- enable them to identify when the person's condition requires action
- assist them to know what to do
- empower them to act when the person has indicated they don't want them to.